

**REPORT
OF THE
MISSOURI HOUSE OF REPRESENTATIVES
INTERIM COMMITTEE
ON
AUTISM SPECTRUM DISORDERS**



January 2010

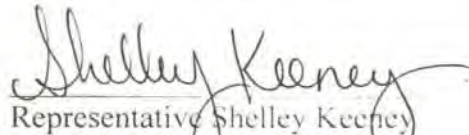
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HOUSE OF REPRESENTATIVES
INTERIM COMMITTEE
ON
AUTISM SPECTRUM DISORDERS
Committee Members


Representative Sue Allen

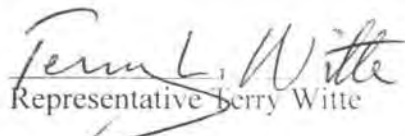

Representative Mike Colona



Representative Sally Faith

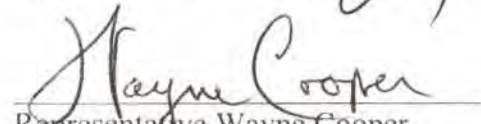

Representative Denny Hoskins

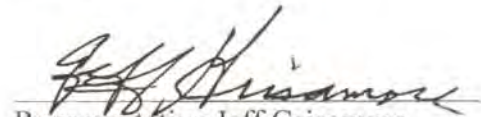

Representative Shelley Keeney


Representative Chris Molendorp


Representative Terry Witte

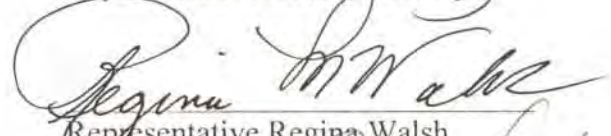

Representative Ron Casey

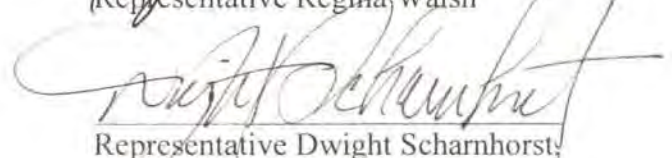

Representative Wayne Cooper,
Vice Chair


Representative Jeff Grisamore


Representative Tishaura Jones


Representative Michele Kratky


Representative Regina Walsh


Representative Dwight Scharnhorst,
Committee Chairman

We, the above-signed members of the House of Representatives Interim Committee on Autism Spectrum Disorders, do hereby respectfully submit our report to the Honorable Ron Richard, Speaker of the Missouri House of Representatives.

To: Ron Richard, Speaker of the Missouri House of Representatives

From: Representative Dwight Scharnhorst, Chair Interim Committee on Autism Spectrum Disorders

Re: Recommendations for consideration as a result of interim committee hearings.

The Interim Committee on Autism Spectrum Disorders was formed and convened to evaluate the impact Autism Spectrum Disorders (ASD) have on the citizens of the state and to consider medical, educational, and insurance policies to improve the lives of families dealing with autism. Over several legislative sessions, bills important to families dealing with ASD have been filed. In the 2009 legislative session, two bills were passed that established the Missouri Parent Advisory Committee on Autism, established five regional autism projects, and required the Division of Developmental Disabilities within the Missouri Department of Mental Health to establish programs and services for people with autism.

The committee commenced its work using the report and findings of the Blue Ribbon Panel on Autism and the Missouri Autism Coalition as a starting point. Public testimony was heard at the committee meetings held in Jefferson City, St. Louis, and Kansas City. Witnesses testified to the medical, educational, and insurance issues regarding ASD.

Autism spectrum disorders is a neurological condition which can respond well with early intervention. Early screening and diagnosis are key to the treatment of children with ASD. Testimony showed that many children may be misdiagnosed and may live in rural or inner city areas with limited access to medical care. On average, the age of diagnosis is later for females and minorities; however, the average age of diagnosis for children with ASD is from three to six years of age. Numerous parents and health care providers offered stories and even video of limitations children with ASD face and the improvement that can be realized with early and appropriate intervention.

Fifteen states have passed legislation that would require health insurance coverage for ASD. With as many as one out of every 150 children diagnosed with ASD in the state of Missouri, the need for action exists. The Department of Insurance, Financial Institutions and Professional Registration testified that mandated coverage for ASD can be enforceable, affordable, and accessible. Testimony from the insurance industry did explain that insurance mandates have historically increased health care costs, and mandates are not their preferred method to provide care to families with ASD.

The committee members heard that, based on actuarial studies, mandated insurance coverage for ASD will have approximately a 1% increase on insurance premiums. The committee heard little testimony from the small business community regarding coverage for ASD. It is the committee's understanding that the impact on small business in the other 15 states that have enacted similar legislation was negligible to slight. Currently, any mandate for insurers to cover ASD would not apply to employers that are regulated by the federal Employee Retirement Income Security Act (ERISA). However, the committee heard testimony speculating that if a mandate is passed, then ERISA-covered entities would feel pressured to provide health insurance coverage for ASD.

One issue at the center of the discussion of ASD insurance coverage is the coverage of applied behavioral analysis (ABA). Testimony from health care providers explained that ABA is a modality or tool that helps children learn, better communicate with others, and improves social

skills. The ABA methodology is an enabling methodology that allows other therapies, such as physical, speech, and occupational therapy to be more effective. Often the prescription for ABA is directly proportionate to the level of severity a child demonstrates. However, research shows that less than 25 hours a week of ABA is not as effective, and the intensity of the service is important.

There has been much discussion regarding whether or not autism services and ABA services, in particular, are medical or educational. While Missouri public schools are charged with the education of children who are developmentally disabled, they are not charged with or responsible for ameliorating medical conditions. Health-related treatments differ from school services in scope, nature, and intensity. However, both health care and education have a role in serving children with autism. Autism is a medical condition. Children with autism require medical services that have to be rendered in the home, community settings, and clinical environments. At the same time, school age children with autism need to be served in the educational setting as well. It is good practice for children receiving ABA treatments to have the service performed both in the home or clinic setting, as well as in the school setting, due to the intensity and amount of service generally required to make ABA most effective.

The committee also heard from several school districts and parents regarding services for children with ASD in the school setting. Some parents testified that services in certain areas of the state are significantly limited when compared with others.

Based upon all the testimony heard by the interim committee, the conclusions that were reached are as follows:

- Most insurance companies exclude coverage for autism specific treatments, particularly ABA, although ABA and other services have been endorsed by the U.S. Surgeon General and other governmental and scientific organizations.
- It is imperative that legislators create a public/private partnership for the provision of autism care. Autism is the fastest growing developmental disability affecting more children than AIDS, childhood cancer, and diabetes combined; all of which are covered by insurance. Autism is a medical condition and Missouri's practice of allowing insurance companies to exclude coverage is discriminatory.
- Passing legislation to mandate insurance coverage for the screening, diagnosis, and treatment of autism, including the provision of services such as ABA, is a priority of this interim committee. The insurance industry's national organizations acknowledge that the cost of this insurance reform is minimal and will have very little impact on the cost of health insurance premiums for the individual consumer.
- By improving outcomes for children with ASD, insurance coverage will decrease the lifetime cost of providing services and will actually result in an overall cost savings to the state and its taxpayers. By continuing to allow insurance companies to prohibit coverage of treatment needed by Missourians, we are effectively passing costs on to state programs. We have an obligation to rectify the situation immediately.

Thus, the findings of the interim committee are that substantive legislation should be passed during the next session of the General Assembly to provide for the effective screening, diagnosis, and treatment of individuals with autism. Behavioral therapies that have been found to be clinically effective, particularly ABA, should be covered treatments that are acknowledged as such within the legislation.